PHOENIX EMA RYAN WHITE

PART A

EMA-WIDE COMPREHENSIVE "OUT OF CARE" PLWHA NEEDS ASSESSMENT

IN MARICOPA AND PINAL COUNTIES, ARIZONA

Report of Findings | July 2011

PHOENIX EMA RYAN WHITE PLANNING COUNCIL

Prepared by:
COLLABORATIVE RESEARCH

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EXECUTIVE SUMMARY

OVERVIEW OF PHOENIX EMA HIV/AIDS EPIDEMIC

The Phoenix EMA's estimated population is 4,281,899, representing 66% of the state's population. The majority or 65.5% of the state population resides in Maricopa County

Arizona is the second fastest growing state in the nation and Maricopa County is the fourth most populous county in the nation. Pinal County is the 7th fastest growing county in the nation among those counties with populations greater than 10,000 persons. The EMA accounts for 74% of the prevalent cases of HIV/AIDS and 77% of the emergent cases of HIV/AIDS. The EMA's population is predominantly White with a significant and increasing Hispanic minority. According to 2009 population estimates from the Arizona Department of Health Services, the EMA's demographics are as follows: 60% White, 4% African-American, 31% Hispanic, almost 2% American Indian, almost 3% Asian, and approximately 2% other or multiple races.

The Phoenix EMA has a combined HIV/AIDS prevalence of 10,492 persons representing a 7.2% case increase over the 2010 prevalence report. Of prevalent cases, 87% are among men, 13% are among women, 57% are White; 12% are African-American, 26% are Hispanic, 3% are American Indian and 1% Asian. *(AZDHS, 2011)* Reported emergent rates of HIV/AIDS in the 2005-2009 time periods are highest in Pinal County (16.63 per 100,000 per year). From 2005-2009, 28% of emergent cases reported in Pinal are among prisoners, many of whom are not originally from Pinal County, or from the state of Arizona (several private prisons located in Pinal County contract with federal agencies and other states to house prisoners). Reported prevalence rates of HIV/AIDS at the time of this report are highest in Maricopa County (242.95 per 100,000).

The EMA's land area is approximately 15,000 square miles. Most persons living with HIV/AIDS in the EMA are centralized in the urban Greater Phoenix Metropolitan area: 95% of the EMA's total PLWHA resides in Maricopa County and 5% resides in Pinal County. The current continuum of care continues to focus on improving access to and retention in care, with an increased emphasis on serving racial and ethnic minorities disproportionately impacted by HIV/AIDS.

RELEVANCE OF THE PHOENIX EMA-WIDE COMPREHENSIVE "OUT OF CARE" NEEDS ASSESSMENT STUDY

This Out of Care survey process was conducted by Collaborative Research, LLC, during the Spring/Summer of 2011. The goal of the survey assessment was to reach at least 50 of the PLWHA population with unmet need in the EMA. A total of 55 persons successfully participated in the 2011 needs assessment survey. The Phoenix EMA has effectively reduced the number of out of care PLWHA from 41 % to 38.4% over the past two years.

Phoenix EMA Unmet Need Estimate *(Data Source: S. Robert Bailey, Epidemiologist, Office of HIV/AIDS, AZDHS)* PHOENIX EMA

CHART CONTINUES ON PG. 5

UNMET NEEDS IN PHOENIX EMA - 2008	CASE COUNT	UNMET NEED RELATIVE PROPORTION	RELATIVE PROPORTION EMA POPULATION
TOTAL PERSONS WITH UNMET NEED FOR HIV PRIMARY CARE		3812	38.40%
PERSONS WITH AN UNMET NEED BY GENDER			
MALES	3342	87.67%	50.52%
FEMALES	470	12.33%	49.48%
TOTAL	3812	.00	100.0%
PERSONS WITH AN UNMET NEED BY AGE			
AGE <2 YEARS	1	0.03%	3.40%
AGE 2-12	2	0.05%	16.82%
AGE 13-19	8	0.21%	9.53%
AGE 20-44	1858	48.7%	6.31%
AGE 45+	1928	50.5%	6.92%
UNKNOWN AGE	15	0.39%	N/A
TOTAL	3812	100.0%	
PERSONS WITH AN UNMET NEED BY RACE/ETHNICITY			
WHITE NON-HISPANIC	2234	58.60%	59.38%
BLACK NON-HISPANIC	505	13.25%	4.50%
HISPANIC	879	23.06%	31.08%
ASIAN/PACIFIC ISLANDER NON-HISPANIC	31	0.81%	3.15%

UNMET NEEDS IN PHOENIX EMA - 2008	CASE COUNT	UNMET NEED RELATIVE PROPORTION	RELATIVE PROPORTION EMA POPULATION
AMERICAN INDIAN/ALASKA NATIVE NON-HISPANIC	74	1.94%	1.96%
MULTI-RACE/ OTHER RACE/ UNKNOWN	89	2.33%	N/A
TOTAL	3812	100.0%	
PERSONS WITH AN UNMET NEED BY REPORTED RISK			
MSM	2130	55.88%	N/A
IDU	517	13.56%	N/A
MSM/IDU	329	8.63%	N/A
HETEROSEXUAL	321	8.42%	N/A
BLOOD EXPOSURE/OTHER	22	0.58%	N/A
MATERNAL VERTICAL TRANSMISSION	10	0.26%	N/A
NO REPORTED RISK/ UNKNOWN RISK	483	12.67%	N/A
TOTAL	3812	100.0%	

OVERVIEW OF EMA-WIDE 'OUT OF CARE' PLWHA STUDY FINDINGS

The 2011 Needs Assessment of surveyed 55 Out of Care PLWHA with unmet need in the Phoenix EMA whose top expressed Needs, Gaps and Barriers for HIV-related services evidence a strong mix of core medical and supportive services.

TOTAL NEED, GAP, BARRIER RANKINGS: ALL 2011 OOC PLWHA

RANK	NEEDS	GAP	BARRIER
1	AOMC	AOMC tied with Medical Transportation	AOMC
2	Medication Assistance	Health Insurance tied with Nutrition Assistance tied with Housing Assistance	Health Insurance Assistance tied with Medical Transportation tied with Mental Health/Social Support Services
3	Nutrition Assistance	Mental Health/Health/Social Support Services tied with Emergency Financial Assistance tied with Other: Homeopathic Services	Medication Assistance
4	Housing Assistance	Medication Assistance	Nutrition Assistance tied with Medical Case Management
5	Mental Health/ Social Support Services	co- pay assistance	Housing Assistance
6	Health Insurance	NR	Other: Homeopathic Services
7	Medical Transportation	NR	Emergency Financial Assistance
8	Emergency Financial Assistance	NR	Non-HIV Medication Assistance
9	Employment Assistance tied with Childcare Assistance	NR	NR
10	NR	NR	NR

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE NEEDS:

1. Ambulatory Outpatient Medical Care (AOMC)
2. Medication Assistance
3. Nutrition Assistance
4. Housing Assistance
5. Mental Health/Social Support Services
6. Health Insurance Assistance
7. Medical Transportation
8. Emergency Financial Assistance
9. Employment Assistance tied with Childcare Assistance

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE GAPS (SERVICES "CAN'T GET"):

1. AOMC tied with Medical Transportation
2. Health Insurance tied with Nutrition Assistance tied with Housing Assistance
3. Mental Health/Social Support Services tied with Emergency Financial Assistance tied with Other: Homeopathic Services
4. Medication Assistance
5. Co-Pay Assistance

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE BARRIERS (SERVICES "HARD TO GET"):

1. AOMC
2. Health Insurance Assistance tied with Medical Transportation tied with Mental Health/Social Support Services
3. Medication Assistance
4. Nutrition Assistance tied with Medical Case Management
5. Housing Assistance
6. Other: Homeopathic Services
7. Emergency Financial Assistance
8. Non-HIV Medication Assistance

These Gap/Barrier service rankings in the above service categories deserve special attention in the priority setting and resource allocation planning and decision making processes for the EMA. The fact that AOMC is a top ranking Need, Gap and Barrier for PLWHA with unmet need is especially concerning and deserves particular attention so that the barriers to medical care may be reduced.

SERVICE GAP REASONS

The reasons the 2011 OOC PLWHA Respondents offer to explain why they perceive certain services are "unavailable" to them primarily focus on lack of funding and perception that services are too costly, and include:

- Low funding
- Make too much money so can't get financial help for cost of meds, etc
- No help with financial aspect – cost of meds, etc
- No insurance
- No financial help
- Services are complicated
- Volunteer shortage

SERVICE BARRIER REASONS

The reasons the 2011 OOC PLWHA Respondents offer to explain why they perceive certain services as "hard to get" are multiple and varied and include:

- Difficult to get in touch with case management
- Distance to services
- Don't have help to find out how to get these services
- Don't talk about HIV freely
- Can't make over a certain amount of income or you get kicked off insurance
- Don't know if they offer behavioral health
- Don't qualify
- Services are complicated; not sure I'm getting the right advice
- Funding cuts
- Hard to get meds on a regular basis
- Knowing where to go for services
- Lack of resources
- Need insurance
- No good doctors; don't treat me right
- Nobody wants to prescribe
- Too expensive
- No access to bus line
- Don't know where to go for services
- Uneducated about what is available

The results of the 2011 Out of Care Needs Assessment Survey reveal a highly impoverished PLWHA consumer group, overall, who present to care with multiple co-morbidities, including high levels of mental health and substance abuse treatment needs, and substantial histories of STDs as well as numerous other chronic illnesses.

CHAPTER 1: INTRODUCTION

BACKGROUND

Annual Needs Assessments are special studies in time conducted to determine the priority service needs, uses, barriers, and gaps in the continuum of care for People Living with HIV/AIDS (PLWHA). Results of this client-centered activity are used to establish service priorities, document the need for specific services, determine barriers to accessing care, provide baseline data for comprehensive planning including capacity building, and help providers improve the accessibility, acceptability, and quality of services delivered, especially to the designated 'Severe Need Groups/Special Populations'.

The Phoenix EMA's continuum of care has evolved into a robust and responsive medical model of HIV care and services delivery. Ambulatory outpatient medical care is supported by a wide range of medically and socially supportive services, including substance abuse and mental health treatment services, medical and social services case management, emergency financial assistance, oral health care, transportation, outreach/case finding and other services essential to facilitating PLWHA access to and retention in HIV primary medical care.

The EMA's ideal continuum of care facilitates optimal access to and full utilization of medical and supportive services. All of these services exist in the context of the five key goals of the U.S. Health Resources and Services Administration (HRSA): 1) improve access to care, 2) eliminate health disparities, 3) improve the quality of care, 4) assure cost effectiveness, and 5) improve health outcomes.

A comprehensive assessment of the service needs, uses, gaps and barriers of "Out of Care" PLWHA within the Phoenix EMA was conducted in the Spring/Summer of 2011. This assessment of need included an "Out of Care" survey questionnaire of PLWHA who have not been receiving Ryan White funded services over the past year, using the Needs Assessment Client Survey (NACS) tool (English and Spanish versions).

PROJECT DESIGN FOR THE 'OUT OF CARE' PLWHA NEEDS ASSESSMENT STUDY

THE OBJECTIVES OF THE COMPREHENSIVE OOC NEEDS ASSESSMENT STUDY WERE:

1. To identify the extent and types of HIV Service Needs among Out of Care PLWH/A with unmet need in the Phoenix EMA; and
2. To identify the HIV Service Gaps and Barriers to care as perceived by Out of Care PLWHA in the Phoenix EMA.

PROCESS USED TO REACH OOC SURVEY RESPONDENTS

- 2,100 Out of Care letters were mailed to clients within the EMA (Oral Health, Pueblo, Care Directions, McDowell)
- Peer outreach was conducted at local food banks and homeless shelters
- Collaborative Research conducted interviews via 1-800 toll free number
- Phone Interviews were conducted from February-July 2011
- A total of 55 Out of Care/Erratic in Care were surveyed

RELEVANCE OF THE PART A COMPREHENSIVE "OUT OF CARE" NEEDS ASSESSMENT

PHOENIX EMA UNMET NEED ESTIMATE (DATA SOURCE: S. ROBERT BAILEY, EPIDEMIOLOGIST, OFFICE OF HIV/AIDS, AZDHS)

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SUBPOPULATIONS MOST LIKELY TO BE 'OUT OF CARE' (OOC)

According to the current Unmet Need Estimate, 38.4% of the PLWHA residing in the Phoenix EMA have an unmet need for HIV primary medical care. The Phoenix OOC population includes those who have been erratically in care, those who have dropped out of care for periods of one year and for greater than two years duration, and those who have yet to enter primary HIV medical care. Of these, almost 87% are males and 13% are females; 49% are between the ages of 20 and 44, with 51% are in the 45 plus age group (the largest single age group among the out of care).

The largest proportions of persons with unmet need are White (59%, followed by Hispanics (23%) and Blacks (13%). Hispanics represent the fastest growing population by race/ethnicity among the out of care and Blacks are most disproportionately represented, when compared to their relative proportion in the EMA (4.31%). When persons with unmet need are examined by risk category, it is evident that, overwhelmingly they are Males who have Sex with Males (56%), followed by IDU (14%), No Reported Risk (13%); Heterosexuals (8%), and MSM/IDU (9%). In fact, when the total Out of Care (OOC) population is examined by risk category, persons with 'any' MSM risk comprise 65% (N=2,459) and persons with 'any' IDU risk comprise 22% (N=846), respectively, of the total unmet need population in the EMA (N=3,812).

In summary, Out of care groups tend to be MSM, IDU or MSM/IDU; the majority of the Phoenix out of care population includes Hispanic and White Males, whose risks include MSM and/or IDU, and are ages 20-44 and 45-plus years; and African Americans/Blacks are disproportionately impacted in terms of the out of care. Aggressive efforts are underway to continue to improve data reporting by primary medical providers in order to ensure complete accuracy of the Ryan White Part A unduplicated client figure.

DEMOGRAPHIC CHARACTERISTICS OF 2011 OOC SURVEY RESPONDENTS

- **Total survey response:** 55 respondents
- **Age range:** 31 to 62 years of age with average age of 45 years
- **Gender:** 71% Male; 29% Female
- **Race/Ethnicity:** 44% White; 29% African American; 15% Hispanic; 7% American Indian; 6% Multi Racial
- **Risk:** 38% MSM; 29% Heterosexual; 22% IDU; 4% Sex with Drug User
- **HIV/AIDS Status:** 71% HIV Diagnosis; 29% AIDS Diagnosis
- **Location of Diagnosis:** 70% Diagnosed in Arizona; 11 % Diagnosed in California
- **Employment Status:** 18% Employed; 82% Unemployed
- **History of Homelessness;** 44% Report history of homelessness (current to within the past 2 years)
- **Income Status:** 51% report incomes of $0-$9,999; 27% report $10,000-$19,999

CHAPTER 2: OOC NEEDS ASSESSMENT FINDINGS

Based upon the Unmet Need Framework, the Phoenix EMA HIV Health Services Planning Council undertook a rapid needs assessment process in order to continue to address the following four items, including any plans for cross-Part collaboration in these areas:

1. Describe the demographics and location of persons who know their status and are NOT in care;
2. Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities;
3. Describe plans to find people NOT in care and get them into care; and
4. Describe how the results of the Unmet Need Framework were used in planning and decision-making about priorities, resource allocations and the system of care.

NOT IN CARE > IN CARE					
UNAWARE OF HIV STATUS (NOT TESTED OF NEVER RECEIVED RESULTS.	KNOWS HIV STATUS (NOT REFERRED TO CARE; DIDN'T KEEP REFERRAL)	MAY BE RECEIVING OTHER MEDICAL CARE BUT NOT HIV CARE	ENTERED HIV PRIMARY MEDICAL CARE BUT DROPPED OUT (LOST TO FOLLOW-UP)	IN AND OUT OF HIVE PRIMARY MEDICAL CARE	FULLY ENGAGED IN HIV PRIMARY MEDICAL CARE

(Source: HRSA HIVCARE Action Newsletter, 2007)

THIS UNMET NEED REPORT IS ORGANIZED AROUND ADDRESSING ITEMS 1 AND 2 ABOVE.

RELEVANCE OF AN UNMET NEED/OUT OF CARE STUDY

Approximately one-third of PLWHA in the United States are aware that they are HIV-positive but do not access primary medical care as defined by the triad of antiretroviral therapy, CD4 and Viral Load laboratory monitoring tests at least every 12 months. The Centers for Disease Control (CDC) estimate that approximately 233,000 of 670,000 Americans who know their HIV status are not regularly receiving HIV primary medical care. (CDC: Ninth Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 2002) Reasons for being Out of Care differ, but occur and re-occur at points along the Continuum of Care.

Four (4) subgroups exist among the 'Out of Care', two of whom do not technically adhere to the HRSA definition of at least one year not accessing primary medical care, but do shed insight into the 'Out of Care' issue. The four (4) groups are: 1) Newly diagnosed (risk of 'ever' attaching to care); 2) Those at 'risk of going Out of Care' (over 6 months not accessing primary medical care, display warning signs of non-compliance with treatment regimens); 3) the 'Technically Out of Care' (over 12 months not accessing primary care); and, 4) the Never in Care.

The initial and significant burden is attaching persons to care immediately upon a positive HIV diagnosis. This juncture is one that many PLWHA recount as 'shock', 'disbelief', 'denial' and often, if co-afflicted with mental health and/or substance abuse issues, regress to numb them from the diagnosis. Curiously, the recent advances in HIV treatment, especially Antiretroviral Therapy (ART) have resulted in person's newly diagnosed taking the news lightly under the misguided assumption that HIV medications can quickly relieve any sickness. These individuals tend to not enter care until they 'feel sick'. In cultures that tend to not disclose or accept illness, particularly ones that are sexually transmitted or incurred due to injection drug use, this pattern exerts a dual deterrent to entering care. The 'late to care' pattern as evidenced by seroconversion to an AIDS diagnosis within a year of being diagnosed HIV-positive is most pronounced among African-Americans, Hispanics, Injection Drug Users, Other Substance Users and the Incarcerated/ Recently Released.

Upon entry to primary medical care, the reasons for detachment include inability or unwillingness to maintain a rigorous treatment regimen (one in which adherence should be 94% or more to attain optimal benefit), side effects of HIV medications, the high cost of drugs or the co-payment related to HIV medications, and the pressure of other subsistence needs such as employment, housing and transportation to either access primary medical care or in lieu of paying for primary medical care.

Key points along the Continuum of Care can be assessed in a study specific to the 'Out of Care' to confirm that these are the risk flags for PLWHA considering abandoning their care regimen. Flags include erratic appointment compliance (missing three or more appointments); tendency to not disclose issues, repeated concerns about medication regimens and drug resistance that may be flags for non-compliance with medication regimens.

The Never in Care are one of the most troubling and least known subgroups. This group evidences resistance issues related to initial attachment to care upon positive HIV diagnosis. Subgroups exist within the 'Never in Care' including PLWHA who self-manage (majority are long-term survivors and wary of HIV medications from the first generation of HIV drugs such as AZT), the 'unconnected' which includes undocumented citizens, the Incarcerated/Recently Released, Injection Drug Users and some Substance Abusers. The Never in Care do not wish to expose themselves to any legal ramifications nor change their current patterns of behavior. Entering medical care is perceived as an exposure risk.

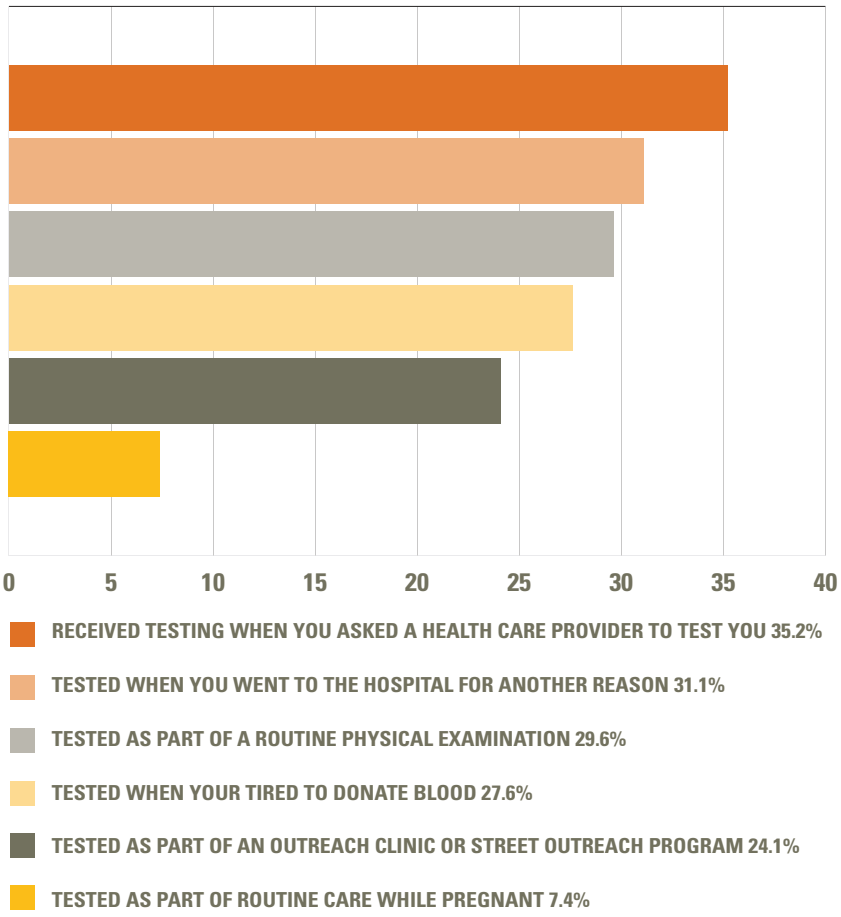
2011 OUT OF CARE NEEDS ASSESSMENT FINDINGS

1. Describe the Demographics, Location and other Characteristics of Persons Who Know Their Status and Are Not In Care

ZIP CODE OF RESIDENCE

At the time of this writing, there is no current location information (i.e. zip code or county of residence) available for the entire OOC population. However, the residential zip codes of all the 55 OOC respondents who were surveyed in 2011 are available and inferences may be drawn from this data and utilized for planning purposes. *A total of 28 various zip codes are reported by the 2011 OOC respondents. According to 2011 OOC survey, clusters of OOC respondents (42%) report their residence in one of five major zip codes, including 85006, 85013, 85019, 85021, and 85031. The remainder of the OOC survey group reports their current residence within numerous other zip codes within the Phoenix EMA.*

TESTING CIRCUMSTANCES

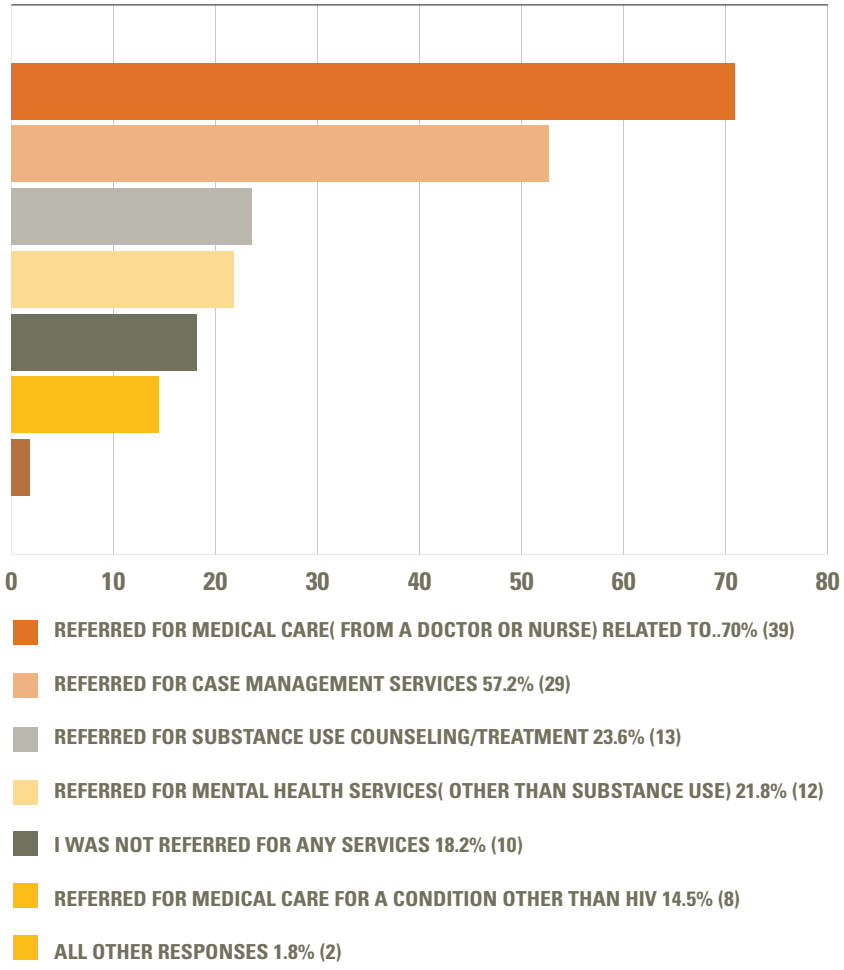


UNDER WHAT CIRCUMSTANCES WERE YOU TESTED FOR HIV AT THE TIME YOU FIRST LEARNED YOU WERE HIV POSTIVE? (PLEASE CHECK ALL THAT APPLY)

Over 1/3 of the OOC respondents report a voluntary request for HIV testing (35%) and another 30% received HIV testing as part of a routine physical examination, however 32% report they were tested when they went to the ER or hospital for treatment of another condition.

REFERRALS FOR CARE AND SERVICES

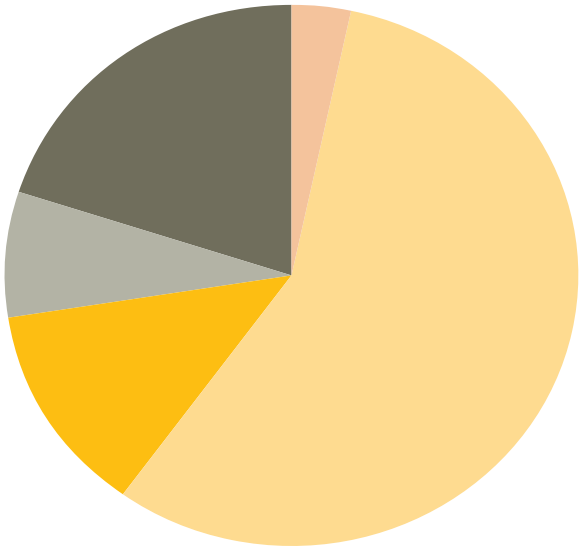
WHEN YOU FOUND OUT YOU WERE HIVE POSITIVE, WERE YOU REFERRED FOR ANY OF THE FOLLOWING SERVICES? INCLUDE ANY SERVICES TO WHICH YOU WERE REFERRED EVEN IF YOU DID NOT USE THE SERVICE. (PLEASE CHECK ALL THAT APPLY)



HIV primary medical care upon learning their HIV diagnosis. This represents a small improvement (from 68% in 2008) and a substantial improvement over the 2006 OOC responses to this item, wherein only 27% of the OOC respondents reported having been directly referred into HIV primary medical care upon diagnosis. Only 18% (increased from 10% in 2008) report NOT receiving any kind of referral and 15% (increased from 10% in 2008) report receiving a referral for non-HIV related medical treatment. A total of 24% of the OOC sample reported receiving a substance abuse treatment referral and 22% report receiving a mental health counseling referral upon diagnosis (increased from 6.5% combined referrals for substance abuse treatment and/or mental health care in 2008).

DELAY FROM TESTING TO CARE ENTRY

PHOENIX EMA OUT OF CARE SURVEY



- I HAVE NEVER RECEIVED CARE FOR HIV 0.0%
- WITHIN 3 MONTHS 56.4%
- WITHIN 6 MONTHS 12.7%
- WITHIN 1 YEAR 7.3%
- LONGER THAN 1 YEAR 20.0%
- OTHER (PLEASE SPECIFY) 3.6%

Over half of the 2011 OOC respondents (56%) report entering care within 3 months of their diagnosis and another 13% report entering care within 6 months. Another 7% report entering care within the first year after learning their HIV status. However, 20% report delaying their entry into care by longer than one year. None of the 2011 respondents reports having never entered care and services.

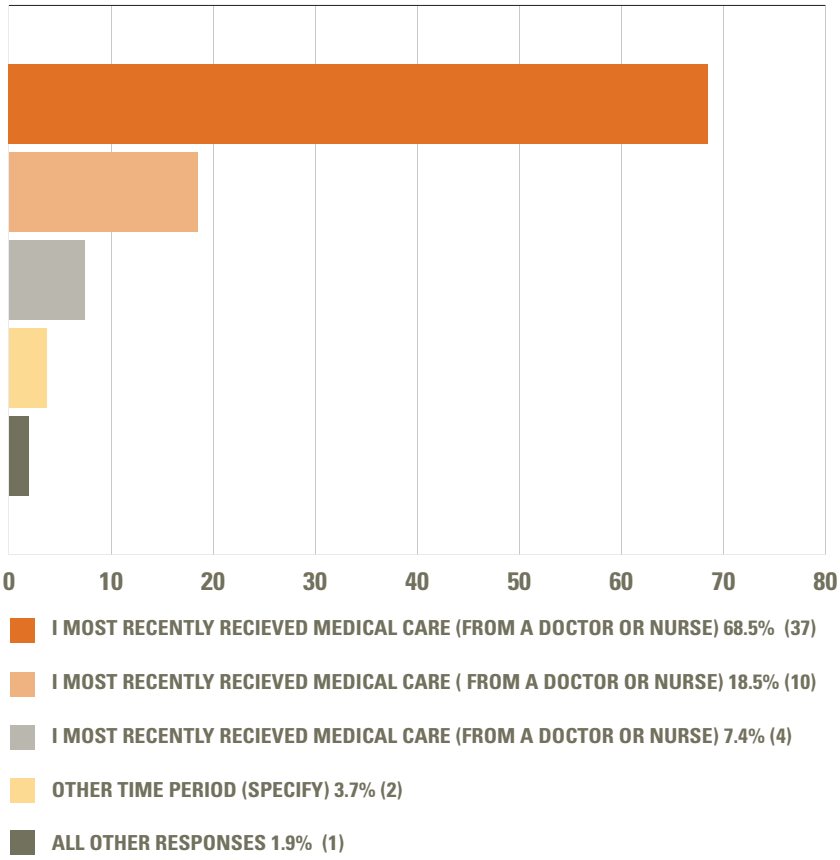
REASONS FOR DELAY INTO CARE OF GREATER THAN ONE YEAR

IF YOU DID NOT SEEK MEDICAL CARE FROM A DOCTOR OR A NURSE WITHIN ONE (1) YEAR OF FINDING OUT YOU WERE HIV POSITIVE, PLEASE INDICATE THE REASONS WHY (CHECK ALL THAT APPLY)		
ANSWER OPTIONS	PERCENT	COUNT
NOT APPLICABLE	74.5%	41
COULDN'T AFFORD IT	1.8%	1
COULDN'T GET TRANSPORTATION	0.0%	0
DIDN'T KNOW WHERE TO GO TO GET MEDICAL CARE	5.5%	3
DON'T TRUST DOCTORS	5.5%	3
DIDN'T THINK I NEEDED IT	18.2%	10
I WAS DEPRESSED	21.8%	12
DIDN'T LIKE THE WAY I WAS TREATED	16.4%	9
OTHER (PLEASE SPECIFY)	5.5%	3
ANSWERED QUESTION 55		

The reasons for delaying care entry center primarily on reports of "depression" (22%); reports of "not thinking they needed care" (18%); and reports of "not liking the way they were treated" (16%). Other less frequently reported reasons included "don't trust doctors" (6%); "don't know where to go for medical care" (6%); and "couldn't afford it" (2%). "Other reasons" included "denial" and "felt healthy".

LAST MEDICAL VISIT

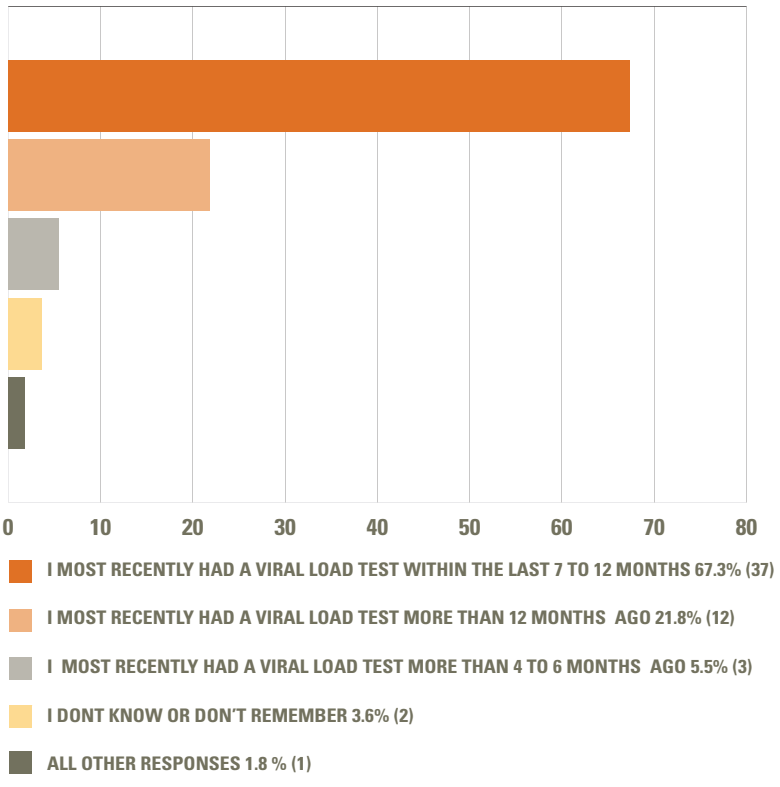
WHEN WAS THE MOST RECENT TIME YOU RECEIVED MEDICAL CARE (FROM A DOCTOR OR A NURSE) RELATED TO YOUR HIV? (PLEASE CHECK ONLY ONE)



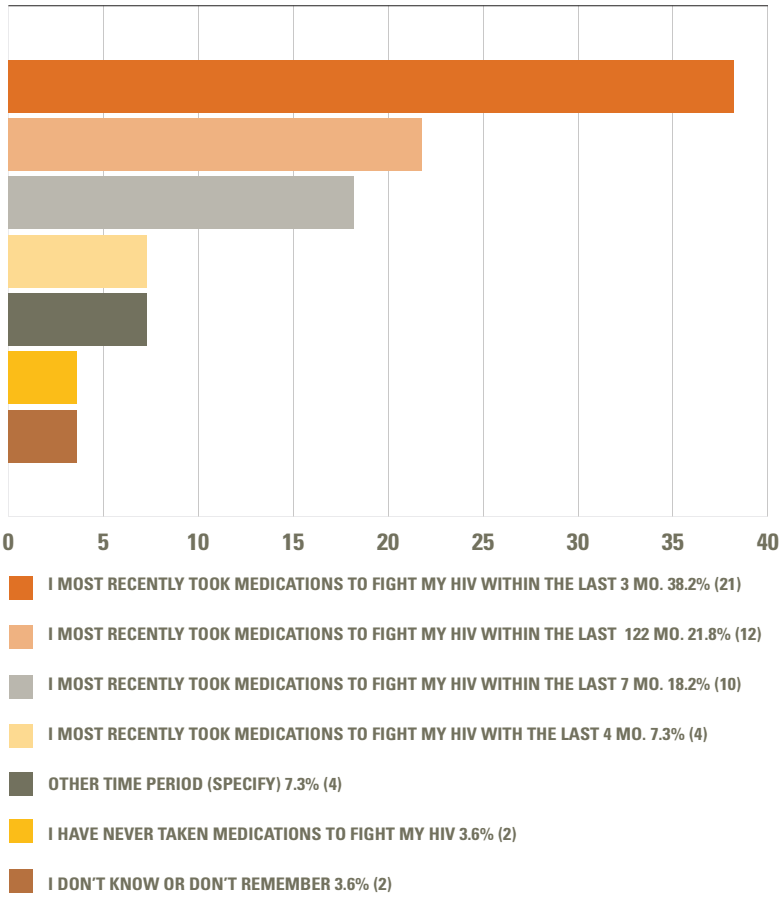
As evidenced above, this cohort of Out of Care PLWHA demonstrates a highly erratic and unsatisfactory pattern of engagement in AOMC services. The majority reports having last seen a doctor or nurse for their HIV treatment from as long ago as 7-12 months previously, with another 19% reporting their last AOMC visit having taken place over one year ago. A minority of the 2011 respondents report receiving HIV care within the last 4-6 months.

LAST LABORATORY MONITORING VISIT

Similar visit patterns are observed with regard to the 2011 respondents' reports of their last viral load measurement, with over 67% reporting their last lab visit 7-12 months ago and 22% more than 12 months ago. A minority (6%) report having had their viral load measured within the past 4-6 months. These reports are most troubling, given the fact that a sizeable minority report continued medication administration without the benefit of routine laboratory monitoring (as evidenced in the diagram on the following page).



LAST ANTIRETROVIRAL MEDICATION ADMINISTRATION



More than 1/3 of the OOC PLWHA reports continuing their ART medication regimens as recently as within the past 3 months. Almost 1/5 reports last taking their ART medications within the past 7-12 months. Over 1/5 (22%) report not taking their antiretroviral medications for more than one year and 4% report never having yet started taking antiretroviral therapy. A minority reports having last taken ART within the last 4-6 months. These reports are concerning, given the relative lack of routine laboratory monitoring reported above.

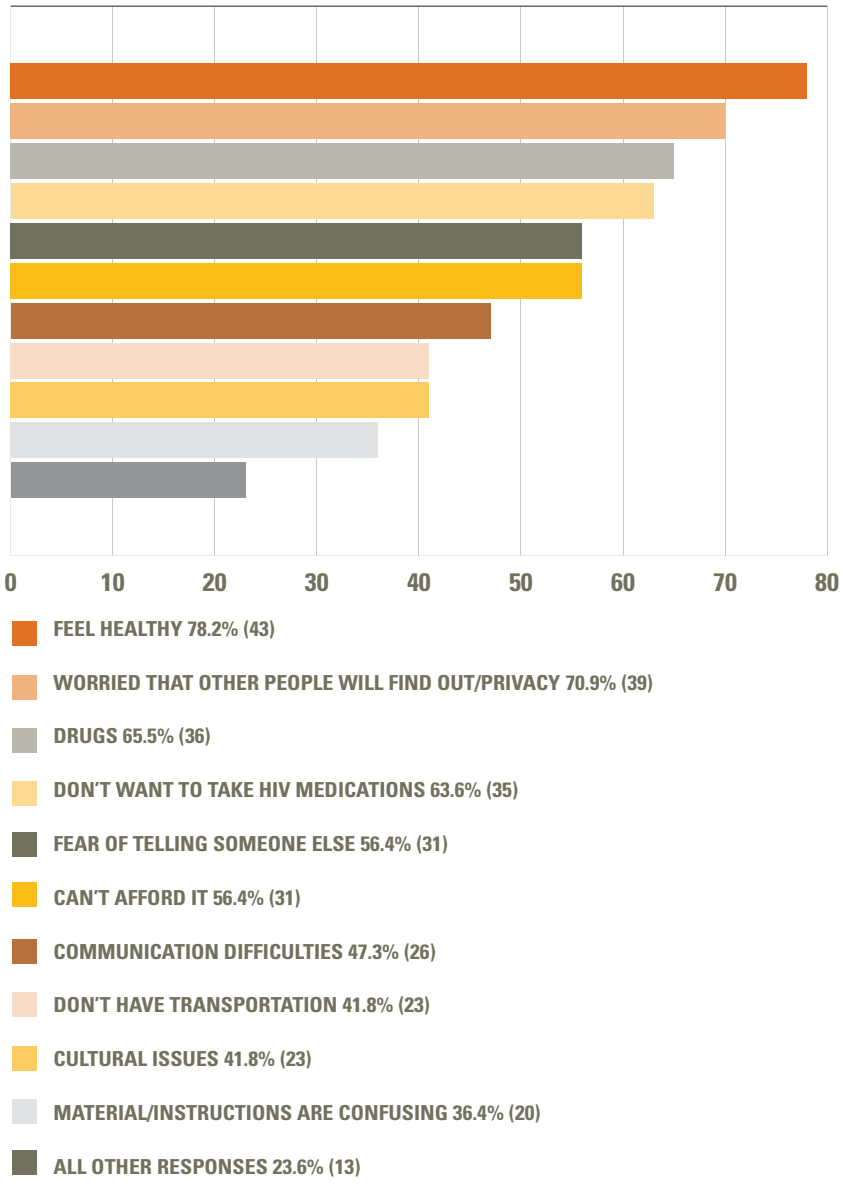
REPORTED REASONS FOR ABSENCE FROM CARE

IF IT HAS BEEN MORE THAN 12 MONTHS SINCE YOU RECEIVED MEDICAL CARE RELATED TO HIV FROM A DOCTOR OR NURSE, PLEASE INDICATE WHY YOU HAVE NOT RECEIVED CARE WITHIN THE PAST 12 MONTHS: (PLEASE CHECK ALL THAT APPLY)		
ANSWER OPTIONS	PERCENT	COUNT
NOT APPLICABLE, I RECEIVED MEDICAL CARE WITHIN THE PAST 6 MONTHS	64.8%	35
I DO NOT THINK THAT I NEED MEDICAL CARE NOW BECAUSE I AM NOT SICK	14.8%	8
I DO NOT KNOW WHERE TO GO FOR MEDICAL CARE	11.1%	6
I CAN'T AFFORD MEDICAL CARE NOW	11.1%	6
I HAVE NOT FOUND A DOCTOR OR NURSE WHO I WANT TO TREAT ME	9.3%	5
I GET ANXIOUS ABOUT GOING TO A DOCTOR OR NURSE ABOUT HIV	7.4%	4
OTHER (PLEASE SPECIFY)	3.7%	2
I LACK TRANSPORTATION TO GET TO MEDICAL CARE APPOINTMENTS	3.7%	2
OTHER (PLEASE SPECIFY)	5.5%	3
ANSWERED QUESTION 54		

The most frequently reported reasons supplied by the 2011 OOC respondent to explain their absence from care include: "I do not need AOMC because I am not sick" (15%); "I do not know where to go for medical care" (11%); "I can't afford medical care now" (11%)' "I have not found a doctor/nurse who I want to treat me" (9%); and "I get anxious about going to a doctor/nurse about HIV" (7%).

BARRIERS TO CARE AND SERVICES

WHY DON'T PEOPLE GET MEDICAL CARE FOR HIV? (PLEASE CHECK AL THAT APPLY)

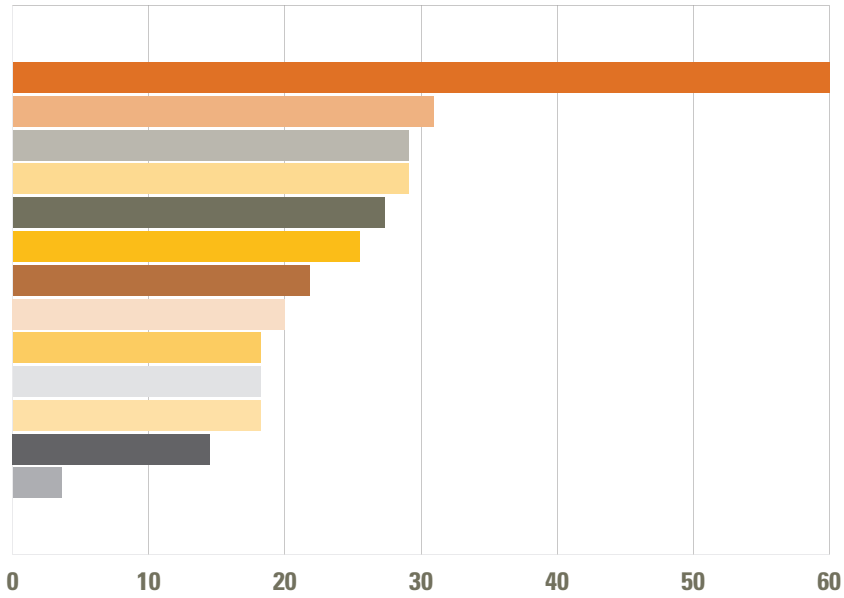


While the vast majority of the OOC PLWHA report "feeling healthy" as the primary reason they are not seeking medical care for their HIV disease, fully 71% report concerns about privacy and worry that others will find out about their HIV status, and 56% report fears of telling someone else about their status.

Fully 2/3 (66%) report that illicit drug use impairs their ability to enter and engage with AOMC and another 64% report they do not want to take antiretroviral medication.

Other frequently reported reasons for their absence from care include: "Can't afford it (565); "Communication difficulties" (47%); "Lack of transportation (42%); "Cultural issues" (42%); "Materials/ Instructions are confusing" (36%); and "other" reports that "Co-pays are difficult".

MOTIVATORS FOR RE-ENTRY INTO CARE



- NOT APPLICABLE 60.0% (33)
- MORE OUTREACH SERVICES30.9% (17)
- ACUTE ILLNESS 29.1% (16)
- BETTER TRAINED DOCTORS AND NURSES 29.1% (16)
- MORE GOVERMENT SERVICES 27.3% (15)
- FREE MEDICAL CARE 25.5% (14)
- MORE INFORMATION ABUT SERVICES 21.8% (12)
- INSURANCE 20.0% (11)
- TRANSPORTATION 18.2% (10)
- BETTER QUALITY SERVICES 18.2% (10)
- REFERRALS OR ADVICE 18.2% (10)
- EMPLOYMENT OPPORTUNITIES 14.5% (8)
- ALL OTHER RESPONSES 3.6% (4)

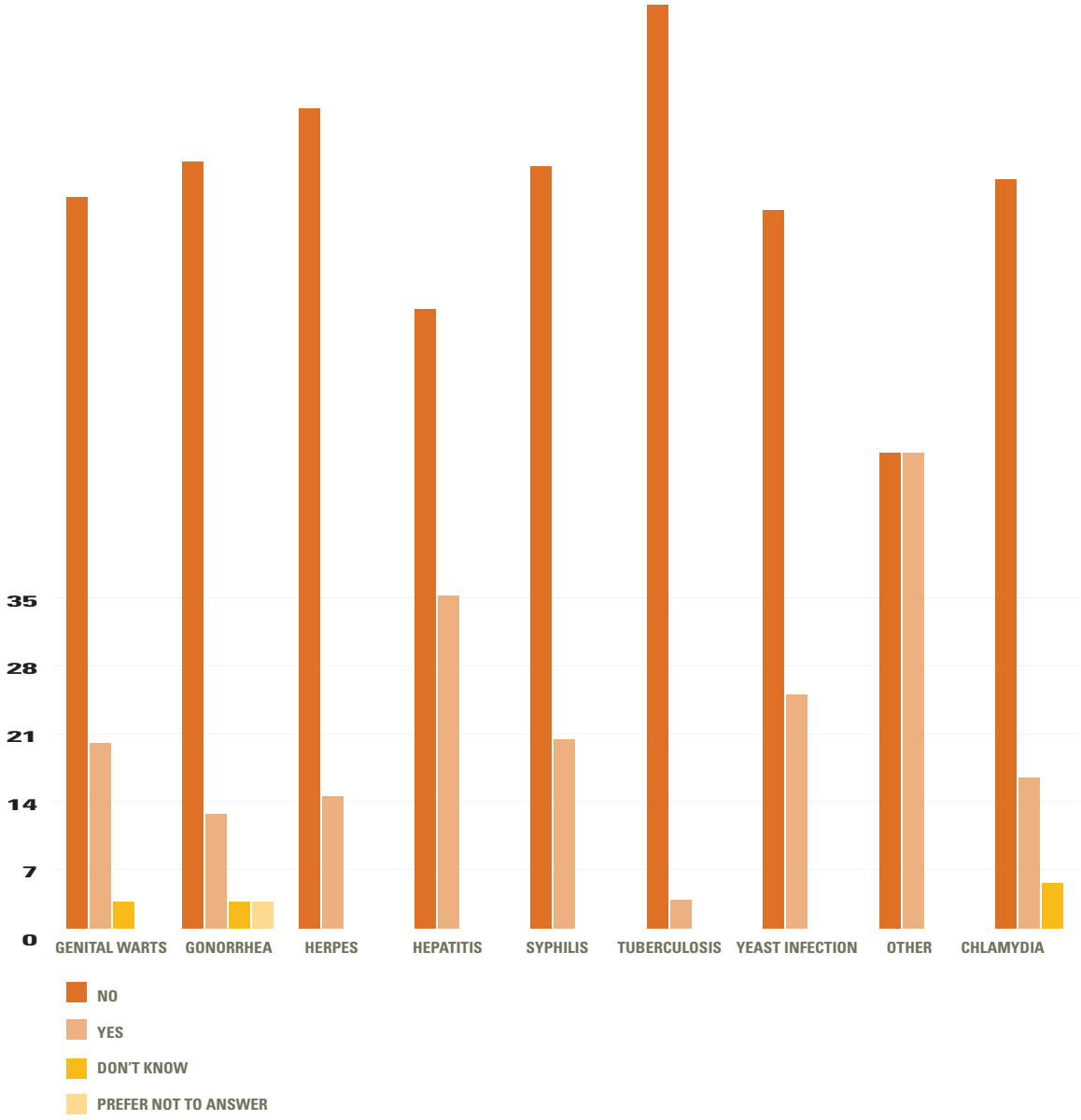
For those PLWHA who have NOT been engaged with primary HIV medical care for periods of time greater than one year, the services they identify as helpful to motivating their re-entry into care include in rank order:

1. More outreach services;
2. Acute illness;
3. Better trained doctors and nurses;
4. More government services;
5. Free medical care;
6. More information about services;
7. Health insurance;
8. Transportation;
9. Better quality of services;
10. Referrals or advice, and
11. Employment opportunities.

Many of these service expansions/changes are amenable to change and should be considered as high priorities for implementation, especially those recommendations pertaining to the expansion of outreach services, increased information about the services available and how to access them, and improved provision of referrals and advice.

STI & OTHER CO-MORBIDITIES

PLEASE INDICATE IF YO HAVE EVER BEEN DIAGNOSED WITH ANY OF THE COMMUNICABLE DISEASES LISTED BELOW BY COMPLETING THE FOLLOWING TABLE: PLEASE CHECK “YES”. “NO”, “DON’T KNOW”, OR “PREFER NOT TO ANSWER” FOR EACH LINE.



The most frequently reported co-morbidities include: Hepatitis (N=19 or 35%); Yeast infections (13 or 24%); Syphilis (11 or 20%); Genital Warts (11 or 20%); Chlamydia (9 or 16%); Genital Herpes (8 or 15%); and Gonorrhea (7 or 13%). Only two OOC PLWHA report the previous diagnosis/treatment for TB, and two other PLWHA report COPD and Thyroid disease.

REPORTS OF OTHER CHRONIC ILLNESSES

HAVE YOU EVER BEEN DIAGNOSED WITH ANY OF THE FOLLOWING? (CHECK ALL THAT APPLY)		
ANSWER OPTIONS	PERCENT	COUNT
EMOTIONAL PROBLEMS (DEPRESSION, ANXIETY, STRESS)	63.6%	35
NEUROPATHY (TROUBLE WITH TINGLING OR NUMBNESS IN YOUR HANDS OR FEET)	30.9%	17
HIGH CHOLESTEROL	29.1%	16
PCP PNEUMONIA	25.5%	14
PROBLEMS WITH THOUGHT OR MEMORY	23.6%	13
DON'T KNOW/NONE	20.0%	11
LUNG/BREATHING PROBLEMS	18.2%	10
CANCER (LYMPHOMA, SARCOMA, ETC)	16.4%	9
LIVER PROBLEMS	14.5%	8
HIGH BLOOD PRESSURE	12.7%	7
KIDNEY PROBLEMS	10.9%	6
DIABETES	9.1%	5
TUBERCULOSIS	3.6%	2
HEART PROBLEMS	0.0%	0
ANSWERED QUESTION 55		

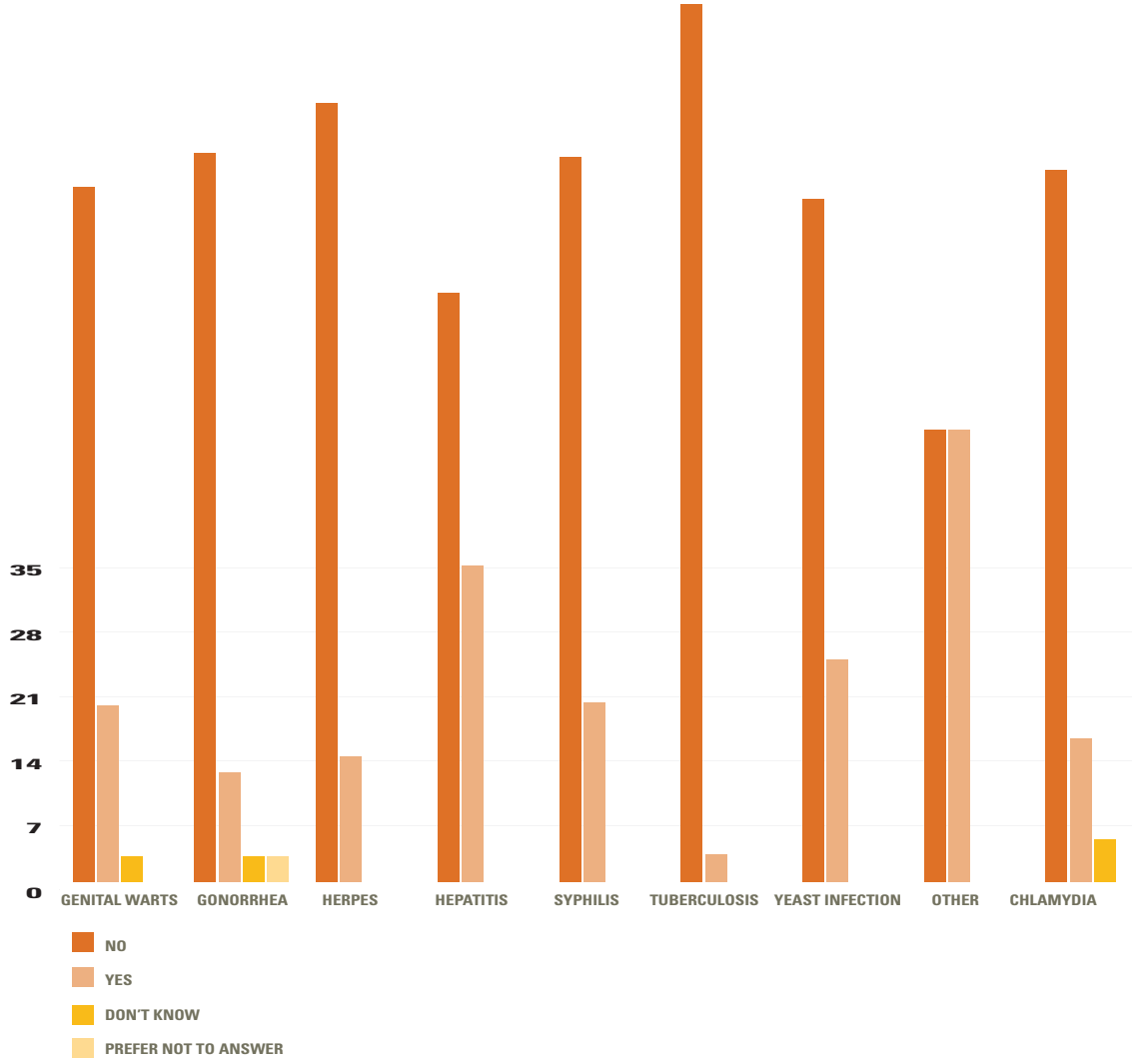
As evidenced in the table above, the vast majority of OOC PLWHA (64%) reports the diagnosis and/or treatment for emotional problems, including anxiety, depression and stress. The next most frequently reported chronic conditions include: Neuropathy (31%); High cholesterol (29%); PCP pneumonia (26%); Problems with thought or memory (24%); Lung or breathing problems (18%); Cancer (16%); Liver problems (15%); High blood pressure (13%); Kidney problems (11%); Diabetes (9%); and TB (4%).

ALMOST 1/3 OR 31% OF THE OOC PLWHA REPORTS TAKING ONE OR MORE MEDICATIONS TO TREAT THEIR EMOTIONAL AND/OR PHYSICAL ILLNESSES, INCLUDING:

- THYROID MEDICATION
- MEDICATIONS FOR COLITIS AND ANXIETY
- LEXAPRO & ABILIFY FOR DEPRESSION
- WELLBUTRIN AND ZYPREXA FOR DEPRESSION
- TRAZODONE FOR SLEEP AND PROPRANOLOL FOR NERVES
- LAMICTAL
- RISPERIZON FOR DEPRESSION AND TENAZEPAN FOR INSOMNIA/ ANXIETY
- ZOLOF FOR DEPRESSION
- ANTI DEPRESSANT
- XANAX, ADDERELL
- PERCOCET

SUBSTANCE USE

DURING THE PAST 12 MONTHS, HOW OFTEN HAVE YOU USED ANY OF THE FOLLOWING SUBSTANCES?PLEASE INDICATE YOUR USE OF EACH SUBSTANCE.

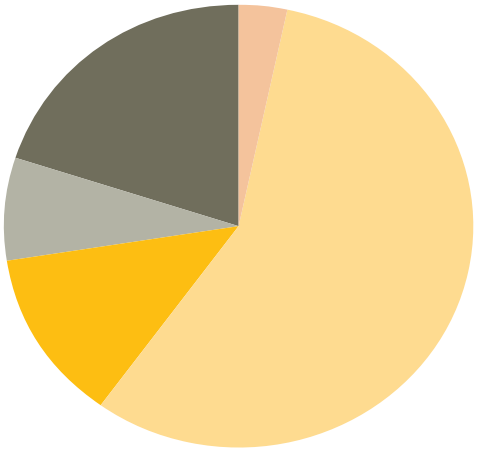


Only 10 of the OOC PLWHA opted to answer the question item regarding alcohol and other substance use. Of those, only one reports daily alcohol use and four PLWHA report daily tobacco use. Weekly reports of substance use include alcohol (N=5); Marijuana (N=1); and Tobacco (N=2)> Monthly reports of substance use include: Alcohol (N=4); and Marijuana (N=2).

EMPLOYMENT, INCOME AND HIGHEST LEVEL OF EDUCATION

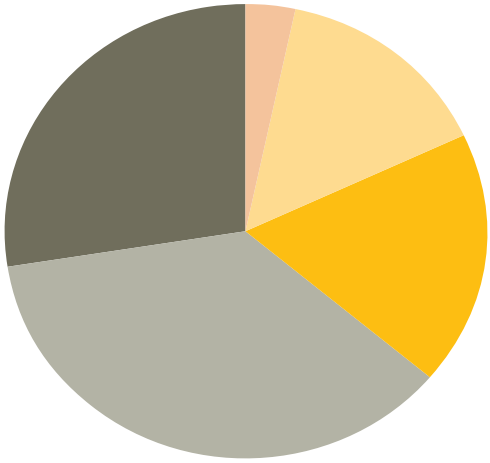
Almost 1/5 or 18% of the Out of Care PLWHA report some employment while 82% report unemployment. Income levels are exceptionally low, as evidenced in the figure below. The vast majority (78%) report incomes at or below $19,999.

PHOENIX EMA OUT OF CARE SURVEYS:



- I HAVE NEVER RECEIVED CARE FOR HIV 0.0%
- WITHIN 3 MONTHS 56.4%
- WITHIN 6 MONTHS 12.7%
- WITHIN 1 YEAR 7.3%
- LONGER THAN 1 YEAR 20.0%
- OTHER (PLEASE SPECIFY) 3.6%

As evidenced below, almost equal fractions of the OOC PLWHA report a high school education or less (36.3%) as do those reporting some college coursework (36.4%). Over 27% report a college degree.



- GRADE SCHOOL 3.6%
- SOME HIGH SCHOOL 14.5%
- HIGH SCHOOL DEGREE 18.2%
- SOME COLLEGE 36.4%
- COLLEGE DEGREE 27.3%

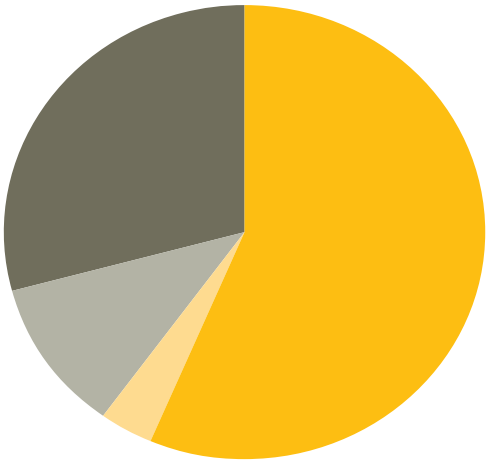
RELATIONSHIP STATUS

The majority of OOC PLWHA reports their relationship status a single (64%), while 18% report being partnered. Equal fractions of the OOC PLWHA report being widowed/partner died (7%) or report being divorced (7%). Only 4% report being legally married.

EVER HOMELESS

Almost 4% of the OOC PLWHA report current homelessness and 11% report homelessness in past two years but not now. Over 29% report a period of homelessness over two years ago; bringing the total reported level of homelessness at some time to 44%.

PHOENIX EMA OUT OF CARE SURVEYS



- NEVER 56.4%
- CURRENTLY HOMELESS (ON THE STREET/IN CAR) 3.6%
- CURRENTLY HOMELESS(HOMELESS SHELTER) 0.0%
- BEEN HOMELESS IN PAST 2 YEARS, NOT NOW 10.9%
- BEEN HOMELESS LONGER THAN 2 YEARS, BUT NOT NOW 29.1%

The current living situation reported by over half the OOC respondents is living in a rented apartment (53%). Another 4% reports living with friends/relatives, while an equal fraction (4%) reports living in a halfway house or other residential treatment center. Almost 40% reports owning or renting a condo or apartment with their partner or room-mate.

2. ASSESS THE SERVICE NEEDS, GAPS AND BARRIERS TO CARE, INCLUDING DISPARITIES IN ACCESS AND SERVICES AMONG AFFECTED SUBPOPULATIONS AND HISTORICALLY UNDERSERVED COMMUNITIES

NEEDS, GAPS, AND BARRIERS RANKINGS

A Needs, Gaps and Barriers ranking was developed for all 2011 Phoenix EMA 'Out of Care' Respondents. The 2011 HIV/AIDS Needs Assessment provides a "snapshot" of the community service needs, barriers, and gaps as expressed by PLWHA with unmet need. This can be further defined as:

NEED	**Number of 'In Care' client survey respondents who stated "I currently need this service."**
GAP	**Sum of 'In Care' client survey respondents who answered 'Yes' to Need and 'No' to availability of that service**
BARRIER	**Number of 'In Care' client survey respondents who indicated that a service is 'Hard to Get'**

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE NEEDS:

1. Ambulatory Outpatient Medical Care (AOMC)
2. Medication Assistance
3. Nutrition Assistance
4. Housing Assistance
5. Mental Health/Social Support Services
6. Health Insurance Assistance
7. Medical Transportation
8. Emergency Financial Assistance
9. Employment Assistance tied with Childcare Assistance

TOTAL NEED, GAP, BARRIER RANKINGS: ALL 2011 OOC PLWHA

RANK	NEEDS	GAP	BARRIER
1	AOMC	AOMC tied with Medical Transportation	AOMC
2	Medication Assistance	Health Insurance tied with Nutrition Assistance tied with Housing Assistance	Health Insurance Assistance tied with Medical Transportation tied with Mental Health/Social Support Services
3	Nutrition Assistance	Mental Health/Social Support Services tied with EFA tied with Other: Homeopathic Services	Medication Assistance
4	Housing Assistance	Medication Assistance	Nutrition Assistance tied with Medical Case Management
5	Mental Health/Social Support Services	Co-Pay Assistance	Housing Assistance
6	Health Insurance	NR	Other: Homeopathic Services
7	Medical Transportation	NR	Emergency Financial Assistance
8	Emergency Financial Assistance	NR	Non-HIV Medication Assistance
9	Employment Assistance tied with Childcare Assistance	NR	NR
10	NR	NR	NR

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE GAPS (SERVICES "CAN'T GET"):

1. AOMC tied with Medical Transportation
2. Health Insurance tied with Nutrition Assistance tied with Housing Assistance
3. Mental Health/Social Support Services tied with Emergency Financial Assistance tied with Other: Homeopathic Services
4. Medication Assistance
5. Co-Pay Assistance

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE BARRIERS (SERVICES "HARD TO GET"):

1. AOMC
2. Health Insurance Assistance tied with Medical Transportation tied with Mental Health/Social Support Services
3. Medication Assistance
4. Nutrition Assistance tied with Medical Case Management
5. Housing Assistance
6. Other: Homeopathic Services
7. Emergency Financial Assistance
8. Non-HIV Medication Assistance

These Gap/Barrier service rankings in the above service categories deserve special attention in the priority setting and resource allocation planning and decision making processes for the EMA. The fact that AOMC is a top ranking Need, Gap and Barrier for PLWHA with unmet need is especially concerning and deserves particular attention so that the barriers to medical care may be reduced.

SERVICE GAP REASONS

The reasons the 2011 OOC PLWHA Respondents offer to explain why they perceive certain services are "unavailable" to them primarily focus on lack of funding and perception that services are too costly, and include:

- Low funding
- Make too much money so can't get financial help for cost of meds, etc
- No help with financial aspect – cost of meds, etc
- No insurance

- No financial help
- Services are complicated
- Volunteer shortage

SERVICE BARRIER REASONS

The reasons the 2011 OOC PLWHA Respondents offer to explain why they perceive certain services as "hard to get" are multiple and varied and include:

- Difficult to get in touch with case management
- Distance to services
- Don't have help to find out how to get these services
- Don't talk about HIV freely
- Can't make over a certain amount of income or you get kicked off insurance
- Don't know if they offer behavioral health
- Don't qualify
- Services are complicated; not sure I'm getting the right advice
- Funding cuts
- Hard to get meds on a regular basis
- Knowing where to go for services
- Lack of resources
- Need insurance
- No good doctors; don't treat me right
- Nobody wants to prescribe
- Too expensive
- No access to bus line
- Don't know where to go for services
- Uneducated about what is available

A lack of awareness of exact service location, lack of knowledge about how to access the services and the lack of funding/lack of insurance are cited by OOC respondents as reasons impeding access to care and services.

ESTIMATED COSTS ASSOCIATED WITH DELIVERING SERVICES TO THE OUT OF CARE POPULATION

"Out of Care" PLWHA represent a significant and increasing burden on the existing continuum of care. While the relative proportion of the Out of Care fraction is actively reduced each year, the numbers of emergent and living cases continue to soar. Upon successful entry/re-entry into care, the intensive needs of this population threaten to exceed available resources. Ambulatory Outpatient Medical Care needs include all of the required comprehensive services for a population with a high level of substance use and high rate of co-morbidities.

CHAPTER 3: RECOMMENDATIONS FOR COMPREHENSIVE STRATEGIC PLAN

The 2010 National HIV/AIDS Strategy for the United States (US) identified three major goals: reducing the number of new HIV infections, increasing access to care and optimizing health outcomes for people living with HIV, and reducing health-related disparities. The Strategy outlines actions to achieve these goals, including increased HIV screening and creation of a seamless system to link newly diagnosed individuals to medical care immediately when they learn they are infected with HIV. (Office of National AIDS Policy (2010) National HIV/AIDS Strategy for the United States. ONAP, The White House)

To support this action, the Strategy recommends that HIV resources be targeted to support linkage coordinators in settings where at risk populations receive health and social services. The Strategy is consistent with the aims of the 2009 reauthorization of the Ryan White HIV/AIDS Program that emphasized the need to examine the size and demographics of the estimated population of individuals with HIV/AIDS who are unaware of their HIV status, as well as the needs of individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services; and linking them to care. (The Ryan White HIV/AIDS Treatment Extension Act of 2009 (P.L. 111-87).

ADDRESS THE TOP RANKING SERVICE GAPS AND BARRIERS OF OOC PLWHA

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE GAPS (SERVICES "CAN'T GET"):

1. AOMC tied with Medical Transportation
2. Health Insurance tied with Nutrition Assistance tied with Housing Assistance
3. Mental Health/Social Support Services tied with Emergency Financial Assistance tied with Other: Homeopathic Services
4. Medication Assistance
5. Co-Pay Assistance

THE OUT OF CARE SURVEY RESPONDENTS RANKED THE FOLLOWING SERVICE BARRIERS (SERVICES "HARD TO GET"):

1. AOMC
2. Health Insurance Assistance tied with Medical Transportation tied with Mental Health/Social Support Services
3. Medication Assistance
4. Nutrition Assistance tied with Medical Case Management
5. Housing Assistance
6. Other: Homeopathic Services
7. Emergency Financial Assistance
8. Non-HIV Medication Assistance

These Gap/Barrier service rankings in the above service categories deserve special attention in the priority setting and resource allocation planning and decision making processes for the EMA. The fact that AOMC is a top ranking Need, Gap and Barrier for PLWHA with unmet need is especially concerning and deserves particular attention so that the barriers to medical care may be reduced.

ADDRESS OOC MOTIVATORS FOR RE-ENTRY INTO CARE

For those PLWHA who have NOT been engaged with primary HIV medical care for periods of time greater than one year, the services they identify as helpful to motivating their re-entry into care include in rank order:

1. More outreach services;
2. Acute illness;
3. RE-ENTRY MOTIVATORS (CONT'D)
4. Better trained doctors and nurses;
5. More government services;
6. Free medical care;
7. More information about services;
8. Health insurance;
9. Transportation;
10. Better quality of services;
11. Referrals or advice, and
12. Employment opportunities.

Many of these service expansions/changes are amenable to change and should be considered as high priorities for implementation, especially those recommendations pertaining to the expansion of outreach services, increased information about the services available and how to access them, and improved provision of referrals and advice.

RECOMMENDED PRIORITY STRATEGIES TO OPTIMIZE UTILIZATION AND RETENTION IN CARE

SUGGESTED STRATEGIES FOR NEWLY DIAGNOSED PLWHA:

Improved links and system navigation between prevention and care, such as:

1. Locating HIV Testing programs in HIV primary clinics, with aggressive offers of testing to the Patients' sexual and drug-using partners, spouses, and friends
2. Expanded use of rapid testing in clinical and outreach testing settings
3. Expanded use of peer outreach testing specialists to locate and test other high risk individuals within their own unique social networks
4. Implementing same day referrals into primary medical care upon testing positive, especially from ER settings
5. Use of peer mentors/system navigators to ease transition into care and assist with navigation of care systems, accompany patients to appointments as needed, and help with reducing barriers to care
6. Implementing service need level assessments which target those persons newly entering care who are most likely to drop out or be most challenging to retain in care, and creating intensive care coordination plans to enhance engagement/retention.
7. Assess funded providers for training needs relative to relationship building and skills development relative to engaging, validating and partnering as key patient engagement and retention strategies, and tailored to meet the unique needs of the special populations

SUGGESTED STRATEGIES FOR PLWHA RECEIVING SOME SERVICES BUT NOT PRIMARY MEDICAL CARE

Improved Linkages between Supportive and Primary Care Services:

1. Medical Case Managers and other Support staff who provide services should implement routine follow-up strategies to inquire about and encourage entry/re-entry into primary medical care for 'erratically' in care.
2. Medical Case Managers and Therapists should ensure that the necessary supportive services are provided to stabilize the person's life situation (i.e., stable housing, food, transportation) and then help ensure that these services are extended to facilitate entry into and retention in care, as indicated, especially for those PLWHA assessed as 'fragilely' in care

3. Expansion of Spanish speaking Therapists and Primary Care Providers and/or interpreters in settings where substantial numbers of non-English speaking PLWHA receive services
4. Perform a cultural awareness/sensitivity assessment with all RW funded providers and offer trainings to ensure cultural competency and age-appropriate delivery of services among funded providers
5. Strengthen mental health and substance abuse treatment and primary medical care linkages; consider co-location of these services wherever possible and ensure ongoing on-site support for PLWHA with mental health and substance abuse co-morbidities
6. Co-locate, to the extent possible, HIV AOMC and other primary medical and specialty care services
7. Strengthen peer outreach to ensure engagement/retention linkages with the most underserved and most likely to disengage.

SUGGESTED STRATEGIES FOR PLWHA WHO HAVE DROPPED OUT OF CARE

Improved Provider-Patient Partnerships and Collaborations with Peers:

1. Primary Care providers should make appointment reminder calls; facilitate transportation assistance; regularly reassess changing needs; and implement/maintain "no-show" tracking and follow-up protocols
2. At least biannually, AOMC providers should examine patient lists to determine who has not returned for care and initiate telephone and/or letter contact and/or peer outreach with individuals to encourage them make appointments and encourage re-entry into care
3. Expand use of peer advocates/peer outreach to locate, help reduce barriers and facilitate re-entry into care
4. Focus on reducing known barriers to care and resolving gaps in the continuum of care, including community-wide strategies for reducing HIV-related stigma

SUGGESTED STRATEGIES FOR PLWHA NEVER IN CARE

Peer-facilitated Linkages between Points of Entry/Testing/Counseling & Primary Care:

1. Active follow-up by Testing/Counseling agency to maintain contact and confirm entry into care
2. Peer Outreach to specific populations and locations, including homeless shelters, drug treatment centers, etc
3. Regular marketing of primary care services' availability and directions on making referrals with all points of entry staff and agencies
4. Social marketing efforts regarding benefits of care and treatment and wide distribution of resource guides
5. Co-location of primary medical care services with mental health and substance abuse treatment/ rehabilitation services
6. Co-location of HIV AOMC, medical specialty and other medical care wherever possible.

APPENDIX